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MENTAL HEALTH CHANGING MINDS QUARTERLY

A Publication of the Massachusetts Department of Mental Health

Volume I, No. 2 Winter 2002

EMERGENCY AND DISASTER RESPONSE

SEPTEMBER 11TH

Federal grants establish MASS Counseling Network

DMH establishes Stress Line to help public cope, find help

If lessons can be learned from the horrific terrorist attacks of September 11, they can be found in the strengths of the Commonwealth's disaster and emergency response infrastructure — a system that was ready and able to respond to the psychological and physical devastation that resulted from that traumatic day, says DMH Commissioner Marylou Sudders.

"There is a sound infrastructure of agencies, organizations and individuals, both private and public, that can be called upon to assure a rapid and sustained response," said Commissioner Sudders. "The significance and magnitude of September 11 showed us that we are all vulnerable and subject to many symptoms of post traumatic stress and flexibility in our response systems is key in our new reality."

While public agencies sharpen their focus on disaster preparedness, several federal grants awarded to DMH funded a number of initiatives — both immediate and ongoing — in response to the terrorist attacks. A Federal Emergency Management Agency (FEMA) award of $702,954 established crisis counseling services, targeted training for crisis counselors and the MASS Counseling Network, a statewide group of 16 DMH providers that delivered group and individual crisis counseling, education, community outreach and referrals free of charge to citizens of the Commonwealth. DMH staff member Darrin Donato reported that more than 10,000 individuals received some kind of service free of charge through November 11, with about 1,500 of those receiving individual crisis counseling.

A major component of the FEMA grant was the establishment of the Department's toll-free stress line, 800-724-8443, which serves as a clearinghouse to connect people in need of crisis counseling and other services in their communities.

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The following essay is one of a series written by DMH Commissioner Marylou Sudders and Deputy Commissioner Kenneth Duckworth, M.D., first appearing in The Boston Globe *and subsequently widely distributed to the public through mental health providers.*

The "New Normalcy"

By Marylou Sudders and Kenneth Duckworth, M.D.

It is tough enough making it through the holidays, emotions intact, during a normal year.

Ongoing terrorist threats make this year anything but normal, and for millions of Americans it will be anything but easy to handle the resultant risk, sadness and even clinical depression.

Consider these reactions we heard recently from two children trying to process what Vice President Dick Cheney has termed America's "New Normalcy" since the tragedies of September 11. Five-year-old Clare passes a bowling alley, spots a poster

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DMH FY2002 Budget: Crisis of a Different Kind

As we make our way through these winter months, the Department normally focuses on our funding needs for the next fiscal year, 2003. Instead, we will be dealing with the results of one of the most difficult budget processes in recent memory where significant cuts to existing services were made.

The Legislature on Thanksgiving Eve, passed a conference budget that eliminated $23.7 million in funding to the Department. This unexpected move would have meant, among a number of things, the closure of nine state hospital wards; the elimination of 334 adults from existing residential programs; and the discharge of 58 children and adolescents from residential settings to their communities.

Through the tireless efforts and strong advocacy of the mental health community, Gov. Jane Swift, in her veto message, filed a supplemental budget that restored $16.6 million to the Department. The Legislature's speedy approval of part of the supplemental bill that included the Department averted a major crisis. I am grateful for the inspiring outpouring from our advocates, consumers, providers, family members and many others who persisted with the message that the safety net for the most vulnerable citizens of the Commonwealth must be preserved. I am confident that this incredible collective energy will carry forward in the next budget cycle.

The Department is still $7 million short for this fiscal year and some painful cuts and reductions in staff and services will be made in the coming months. While the Department deals with these issues, we must bear in mind issues of a more global nature — that the trauma from the horrific terrorist attacks of September 11 and the continued threat of bioterrorism still reverberates for the citizens of the Commonwealth. This is not only true for the immediate victims, families, first responders and rescuers of that terrible day, but also for the the public at large. The Department of Mental Health, in addition to its role of ensuring services to severely mentally ill citizens, is also responsible for the mental health of the general public. To this end, it is gratifying to report in the Winter issue of the MENTAL HEALTH QUARTERLY that the Commonwealth's Disaster Mental Health and Substance Abuse Services Committee has re-formed with new resolve and commitment to our preparedness in the face of disasters and emergencies, natural and otherwise.

This committee is comprised of people of great depth and experience in their respective fields of public safety, human services, emergency management and public health and, with full partnership and commitment from DMH, it is my hope that this group maintains its momentum as we navigate the waters of a troubled world.

Marylou Sudders

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DEPARTMENT OF MENTAL HEALTH

Jane Swift
Governor

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End-of-Life Research Project a First in the Nation

As awareness for the need to provide quality end-of-life care grows, DMH clinicians in the Metro Suburban Area are developing a model to include individuals with serious mental illnesses.

Although significant understanding now exists in the field of pain control and in the importance of promoting autonomy and choice, none of these studies explore such issues in the mentally ill.

The project, a first in the country to focus on these issues, is funded through the Robert Wood Johnson Foundation and was one of 22 grants selected from 678 proposals submitted to the Foundation's "Promoting Excellence in End-of Life Care." Its principal investigator, Mary Ellen Foti, M.D., Metro Suburban Area Medical Director, said that although significant understanding now exists in the field of pain control and in the importance of promoting autonomy and choice, "none of these studies explore such issues in the mentally ill."

Dr. Foti said that she first became interested in the study of death and dying during her first year at the University of Massachusetts Medical School. In "Medical Arts and the Humanities," a course created and taught by Sandra Bertman, associate professor of humanities in medicine, Bertman designed and taught the course to prepare students for lab work with cadavers, often a traumatic experience as well as being their first close contact with death. "It became a touchstone for me," Dr. Foti said.

Later at New England Medical Center, she worked with staff, patients and families in the role of consultation liaison. It was there that she learned how effective a psychiatrist could be as part of a team working to help the very sick and their caregivers. This led her quite naturally to public sector psychiatry and eventually to the end-of-life care study for the mentally ill.

It is a law that every patient, at the time of admission to a health care facility, such as a hospital or nursing home, be asked whether he has a health care agent. The agent is authorized to act for the patient in the event that the patient was unable to communicate his own wishes regarding treatment. Dr. Foti's studies revealed that, although Massachusetts state facilities were 95 percent compliant with this law, only one psychiatric patient out of 366 had arranged for a health care proxy.

Why was this so? As the project progressed, it became apparent that questions of competency presented major barriers for staff to pursue proxy issues for people experiencing symptoms of mental illness. Do patients understand their own illness? Can they appreciate the role of a health care agent? Do they possess the reasoning abilities to make choices? Would the subject be too upsetting to discuss with them?

Dr. Foti set out to answer these questions and here are some of the stories she tells.

Even before the health agent mandate became law, a group home in Arlington had cared for a terminally ill resident who did not want to go to the hospital or move to a nursing home. Lacking experience with end-of-life medical care, the home's director talked with staff and other residents. Deciding to take on the patient's request, they met with hospice workers who agreed to join them, engendering the participation of all involved. Staff learned the necessary medical procedures while fellow residents sat by his bed, brought flowers and assumed new chores.

More recently, a long-term patient at Westborough State Hospital became seriously ill. He had already designated a niece to be his health care proxy. She knew he didn't want to leave his unit and staff agreed. Known to all as "The Major," he had, after more than twenty years, become a fixture, said Foti. Local hospice staff held an afternoon meeting on his unit and so concerned were staff about his care, that everyone from day and evening shifts crowded into the conference room. As his illness worsened and his pain increased, he became belligerent and difficult to care for, but with the help of hospice, his treaters and friends, he died a peaceful death on his own terms.

Now at the end of the third year of the end-of-life project grant, Dr. Foti and her colleagues are in the process of analyzing the data. Yet to come is a brochure about health care agents designed for the psychiatric population and their loved ones. A companion workbook for clinicians will follow. The Massachusetts model includes a collaborative network of hospice care and mental health providers. Hospice care work-

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Other components include crisis counseling training for both DMH and provider professionals; services to homeless individuals; DMH clients and staff in community settings; the elderly and veterans; state employees; and persons of Middle Eastern, Islamic and other ethnicities. In conjunction with the Massachusetts Bay Chapter of the American Red Cross, DMH provided crisis counseling to the families and friends of victims of the airplane crashes and the World Trade Center collapse.

A second federal grant of $50,000 was awarded to DMH by the Substance Abuse and Mental Health Services Administration (SAMHSA) and Center for Mental Health Services (CMHS) to conduct a needs assessment for the Department's disaster mental health services and infrastructure. Part of this funding provided short-term crisis and stress management to inpatient clients through DMH staff. The Department also purchased three laptop computers and software to establish a mobile mental health response deployment base.

Another SAMHSA/CMHS grant established a collaboration between DMH and the Department of Public Health and reaches beyond the scope of the FEMA crisis counseling and training grant. DMH and DPH each received $575,000 to boost both agencies' capacity to respond to disaster in a sustained way through enhanced programs and emergency infrastructure.

A DMH-DPH Project Steering Committee formed late in the fall, headed on the DMH side by Deputy Commissioner Ann Detrick and Walter Jabzanka; DPH efforts will be led by Associate Commissioner Deborah Walker, Carolyn Castro-Donlin and Karen Pressman.

The Committee identified training, public education and school outreach as three top priorities in preparing for and responding to disasters. Plans call for convening work groups with the state Department of Education to review the material currently available on how teachers and parents can address the impact of terrorism on school-age children. Developing new fact sheets, videos and curriculum will be part of this task as well as ensuring that child-centered material is delivered to providers in the community.

DMH, DPH and DOE will also collaborate on training agendas for clinical staff. Training protocols need a fresh look in light of the unprecedented effects on the emotional well being of the general public post-September 11. The updated training will be available to

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Sen. Kennedy thanks DMH disaster counselors

Sen. Edward M. Kennedy visited a DMH emergency and disaster response training event, thanking all for their efforts in assisting victims' families in the aftermath of the September 11 terrorist attacks.

Sen. Edward M. Kennedy paid an special visit to a Department of Mental Health disaster training at the Dr. Solomon Carter Fuller Mental Health Center in Boston to thank DMH staff for their counseling work in the aftermath of September 11. Sen. Kennedy took a personal interest in helping the families of victims of the two airliners hijacked out of Logan International Airport, meeting with family members and offering his assistance and support.

Commissioner Marylou Sudders introduced Sen. Kennedy who spoke eloquently about the importance of mental health crisis counseling to those affected by the events of September 11th. The Senator expressed his gratitude to those clinicians who would be contacting constituents in need while reiterating his pledge to seek additional federal assistance to victims, survivors and families.

The training, planned after the tragic events of September 11, was designed for selected service providers in the Metro Boston and Northeast areas who were chosen to deliver disaster mental health services through the newly formed MASS Counseling Network. Darrin Donato, of DMH, outlined criteria for FEMA grant awards and the basis for the establishment of the MASS Counseling Network, a sixteen-member, non-profit provider collaborative that will provide the lion's share of post-September 11 crisis counseling and outreach to victims, families and affected populations throughout the state.

Louise Carcione, Metro Boston Area Emergency Management Coordinator, talked about the role of DMH and its public safety partners in disaster response. Other presenters included Hayden Duggan, a Boston public safety expert who stressed the importance of critical incident stress debriefing to enable first responders to stay on the job; Jim Munroe of the Massachusetts Bay Chapter of the American Red Cross, who detailed the ARC/DMH interagency collaborations in times of disaster; and Bette Spear, who detailed grief counseling techniques on behalf of the Massachusetts Office for Victim Assistance.

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clinicians in school systems, in substance abuse agencies and others practicing in the community. The hope is that, once trained, their names will be added to the current DMH roster of eligible disaster responders.

The DMH-DPH Committee is exploring the best strategies for disseminating wellness materials and information to the general public, including creating a Web site that will provide a wealth of referral information and Internet links to related sites as well as translating the material into several languages.

One of the most significant public health and safety measures taken post-September 11 was the re-formation of the state's Disaster Mental Health & Substance Abuse Services Committee. Bud Iannazzo of the Massachusetts Emergency Management Agency (MEMA) and Commissioner Sudders convened the group on December 13 at the MEMA "Bunker" in Framingham. Parallel to the scope and magnitude of September 11, membership on the reconstituted disaster committee reflects a broader reach across the the community than in the past. New representation comes from DPH, DOE, the Massachusetts Hospital Association, Massachusetts Office for Victim Assistance and other faith-based, human services and civic organizations.

Addressing members gathered for the re-launch, Commissioner Sudders highlighted the Commonwealth's already strong disaster response infrastructure. "But because the trauma of September 11 and the continued threat of bioterrorism is experienced not only by those immediately affected, but also by the larger community, we must be able to respond to both individual and collective trauma.

"Our successful response," she continued, "includes effective outreach, intervention collaborations, information sharing and more research."

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showing hands and an American flag, and asks, "Are people in the bowling alley also praying for all the people who died in New York?" Elizabeth, an 8-year-old, says, "This whole New York thing must be really, really big ... everywhere you go people are talking about it." Those children's simple observations make clear the New Normalcy is neither normal nor escapable, even if we limit our exposure to the media.

So what can we do, for ourselves and our children, as we enter this Thanksgiving/Christmas/Chanukah/Ramadan/Kwanzaa season of rising demands and expectations?

Coping strategies are more important than ever, and involve all the supports we can muster to deal with these unsettling times. Celebrate strong family ties. Family and friends are invaluable, particularly now. Talk about your feelings and worries, whether it is over coffee or in a support group. Altruism and humor are stellar psychological coping mechanisms. Giving to local charities and our local communities is a way to do something good. We hate to feel helpless; positive action can be healing. Writing checks to relief agencies can substitute for items on your holiday gift list. It is natural to want to change unpleasant emotional states, however some tactics can be counterproductive. Drinking alcohol or abusing drugs as ways to "self-medicate" anxiety is ill-advised.

Other ways to cope include:

Exercise – Studies scientifically demonstrate that aerobic exercise reduces anxiety and depression. Kids often rely on action more then words, and are particularly sensitive to the need to get the carbon off their valves. Exercise is also a great sleep aid.

Turning Passive into Active – Children, like adults, hate helplessness. Working with a school, church or community organization gives us the opportunity to participate in something bigger than ourselves.

Denial – This is an underrated strategy if ever there was one, especially in regards to catastrophic and air travel scenarios, although it should be used in moderation.

Prayer – Your children already know about these events and it is okay to include in their holiday prayers hopes for peace and relief for people who have suffered.

Structure and Rituals – Kids, like adults, are reassured by rituals and routines. If you choose not to travel, keep as many things as similar as you can. Remember the adage that "all perspective is local," so the menu and the tone you set will dictate their response.

Alternative remedies – Yoga, acupuncture, meditation and biofeedback all are anti-anxiety strategies. And none have side effects.

As professionals in the field, we have observed a soaring demand for mental health services statewide. The Department of Mental Health, with funding from the Federal Emergency Management Agency, established the MASS Counseling Network. Since September 11, we have provided services to 10,053 citizens: individual and group counseling; community outreach, forums with churches, communities, schools and human services agencies; and counseling for first responders, to name a few. There also is a toll-free Stress Line for the public at 1-800-724-8443.

How do you know whether you need help? Ask yourself these questions: Is anxiety causing you to consistently fall behind at home or school? Is sleeplessness substantially impairing concentration so you feel consistently off your game? Post-traumatic stress disorder (PTSD) is a psychiatric condition that we know the cause of – extreme events – but it is less clear why one develops symptoms. Triggers can include a history of war service, having had to evacuate a building after a bomb threat, being victimized by crime or even abuse as a child. Losses that are a sad fact of living, such as a death of a relative, can add to the risk.

But as mental health professionals we also have observed, again and again, the resiliency of the human spirit. In these times of heightened anxiety, we encourage you to draw upon those you love and your time-tested coping strategies to provide your children with a model for handling the New Normalcy: they are learning from us and, like us, want to feel safe again.

Young Adults with Mental Illness Making a Difference

By Jonathan Delman

Turning 18 for most teenagers means enjoying new-found freedoms. This often turbulent transition, however, is a Catch-22 for teenagers struggling with trauma issues, depression, substance abuse and other emotional difficulties. While these young adults are now free to make choices about the mental health services they receive, they find themselves eligible for fewer service options provided by an adult system with a very different focus and expectations. Consequently, many troubled young adults stop getting treatment altogether.

The Massachusetts Consumer Satisfaction Team, Inc. (MCST), a Dorchester-based organization run by individuals using mental health services, was awarded a $25,000 grant from the Center for Health Care Strategies (CHCS) through the Robert Wood Johnson Foundation to help these young adults develop leadership capacities to inform key policy makers what their needs are as they "age out." Called the "Young Adults in Transition Citizenship Project," it is based on the belief that young adults who have experienced this transition themselves can best inform state policy makers about their needs.

The purpose of our organization is to help disenfranchised groups gain a voice in program planning and policy making. It is gratifying that key state agencies and stakeholders, including the Department of Mental Health (DMH), Division of Medical Assistance (DMA), Massachusetts Behavioral Health Partnership and Department of Social Services (DSS) support this process.

Although much media attention has been focused on the crisis in children's mental health care, little has been written about the lack of guidance that accompanies older teenagers who are expected to face many of their psychiatric issues alone. According to MCST's project consultant, Maryann Davis, Ph.D., Department of Psychiatry at the University of Massachusetts, Worcester, one-third to one-half of adolescents receiving services do not continue to do so as adults. At the age of 18 or 19, adolescents become legal adults and are responsible for their own care. They may lose the health coverage of DMA and/or DMH and possibly the "care and protection" of DSS. More likely, they simply opt out of an adult system that does not meet their needs.

Although many young adults who opt out of continued treatment go on to further their education or find work, keeping their lives structured and purposeful, others are unable to do so. Instead, they find themselves with substance abuse problems, involved with criminal activity, homeless or some combination of the above. Their transition to adulthood has become a trauma that in itself can require treatment.

The Young Adults in Transition Citizenship Project works in three stages: 1) face-to-face interviews with a diverse group of young adults with mental illness to gather a database; 2) leadership training for a council of young adults to advocate for systems of care that meet their needs; 3) establishment of formal young adult advisory council to provide ongoing direction and feedback to relevant mental health policy makers and the state Legislature in planning systems that maintains the health of adolescents who age out.

We at MCST hope these efforts will help lead to the construction of a bridge between the adolescent and the adult mental health systems that can best serve the state's young adults.

Jonathan Delman, J.D., is executive director of the Massachusetts Consumer Satisfaction Team, Inc.

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ers will learn about diagnostic criteria, new medication therapies and drug interactions specific to psychiatric patients. "Most importantly, we teach them how to feel comfortable communicating with a person who has a serious mental illness," said Dr. Foti. The director of the MacArthur program hopes Foti's demonstration project will allow others to start testing ideas and addressing barriers so that we can "take the information to policy makers and enact change."

Initial inferences suggest that people with mental illness want for themselves the same sort of care that the rest of the population wants and that they share the same concerns and fears. They don't want to be a burden to their families; they understand Do Not Resuscitate (DNR) orders and they know how they feel about this procedure. It is Dr. Foti's hope that within the next three years, every patient in the state will have had the opportunity to select a health care proxy, including the mentally ill, a population, she says, that the "medical establishment has traditionally overlooked."

Making life and death decisions are not made easily by anyone, but Massachusetts' law ensures that everyone has the right to do so. Dr. Foti has maintained from the beginning of this project that for the mentally ill, this has been another stigma issue."

For more information on "the End of Life Care Project," contact Mary Ellen Foti, M.D., Area Medical Director, Medfield State Hospital, 508-242-8000.

Human Rights in Action

By Carol O'Loughlin and Bernadette Drum

Since 1984, the Department of Mental Health has sponsored its annual Human Rights conferences — an event planned and organized by the Human Rights Advisory Committee and much anticipated among consumers, ex-patients, advocates and mental health workers.

The current fiscal year's scarce resources has forced the Department to cancel one of its biannual events, the 2002 Spring Human Rights Conference. Nevertheless, our commitment to human rights and the training opportunities associated with the spring and fall conferences remains steadfast and undiminished. We are in the process of planning a fall training event that will return the focus to basic skills. While our conferences have expanded to include a multitude of varied offerings that reflect the richness and diversity of our constituencies, we need to provide human rights personnel the tools they need to advance our mission.

The need to provide a well-prepared and comprehensive human rights curriculum for human rights coordinators and officers in our community programs for children, adolescents and adults is very real. Every consumer served by DMH is entitled to know that there is a consistent statewide platform built on statute and regulations that assures them that their human rights will be respected.

As we plan for the fall conference with a renewed focus, we acknowledge the unique features of this event — DMH human rights conferences are well known for diverse audiences, with many consumers and family members both presenting and in attendance. Joining them are human rights staff and committee members, staff and clinicians, DMH managers, contracted agencies and other interested people. To this end, we are examining ways to best assess and then address the needs of the people who serve not only as human rights coordinators and officers, but also those who volunteer their knowledge, time and passion to the cause of human rights. Our plans will rely on a strong consumer voice, since this is the voice of experience with a wealth of knowledge to offer.

The last Human Rights Conference held in the fall of 2001 is a good example of how workshops with diverse content are held alongside basic workshops designed to train new human rights officers, including two on the DMH complaint and fact-finding processes, both of which are described under Massachusetts regulation (104 CMR 32.00).

Every consumer served by DMH is entitled to know that there is a consistent statewide platform built on statute and regulations that assures them that their human rights will be respected.

Workshop samplings included alternative dispute resolution, negotiation skills and "The Circle" process, borrowed from Native American tradition; alternative treatments such as working with nature and animals; using the arts to promote wellness in at risk youth; and the importance of spirituality in recovery.

New to the lineup was a workshop on voter's rights for DMH consumers. This often overlooked but very important human rights issue is based in the National Voter Registration Act (NVRA) of 1993, which became effective in Massachusetts January 1, 1995. While better known as the "Motor Voter Law" because of its mandate to allow voter registration with motor vehicle driver's license application or renewal, NVRA also requires states to offer voter registration services through all state agencies that provided services to people with disabilities. The Department of Mental Health is one of those agencies.

The voter rights workshop brought to light the need to explore the outer reaches of human rights issues. While many issues occur repeatedly — and we strive to identify these topics and address them — there are many issues that arise for the first time and appear to present unique considerations, such as voting rights for consumers. It is here we will reach for a balanced approach — our training curriculum should provide the skills necessary to handle both of these situations and all others on the points of the spectrum that connects them. This column is one vehicle we will use to communicate the planning process to our constituents.

Despite the enormous success of our conferences, there is always more that can be done to optimize human rights training opportunities. An active effort is underway to assess the training needs of staff and clients statewide. When complete, a task force will be established to develop a training model that best addresses the needs of human rights officers whose role it is to train Human Rights Committee members and others in a variety of settings. Our goal is to develop a dynamic curriculum for specific skills and establish ongoing support and dialogue among human rights officers and committee members locally and statewide.

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